
CIRM sends Patient advocates to international stem cell meeting

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Today stem cell scientists and patient advocates are descending on Toronto for the annual meeting of the International Society for Stem Cell Research. Among those registering and preparing for three days of science is Don Reed, who is one of 20 patient advocates who received a CIRM stipend to attend.

On his blog today, Reed writes about his trip to Toronto and the important role of patient advocates in promoting science:

“ Patient advocates like my son Roman Reed are the emotional muscle behind research for cure. It is not easy for a paralyzed person to travel, but he will be there, listening and learning, and speaking.

Because there will be funding fights ahead, both nationally, and in every state.

When a politician says, "We can't afford to fund the research"-someone must be there to say: "We cannot afford NOT to fund the research-and here's why." That someone is us. If it is just the scientists talking, it is all too easy for politicians to ignore them.

Think of the numbers. There are only a handful of top research scientists. Politically, they are negligible. If they only talk to each other, they might as well pack up their test tubes and go home, because they will never get public funding.

But there are millions of patients and familyâ patient advocates. Working together, we cannot be ignored. From its inception, CIRM has recognized the importance of patient advocate voices in scientific decision-making, including ten such advocates on our governing board (bios of all board members are available here). Jeff Sheehy, patient advocate board member for HIV/AIDS blogged about his role on our board:

“ I serve on the governing board as a patient advocate for HIV/AIDS, and in that role I along with the other patient advocate board members have been able to directly influence the direction of the agency. Our voice has helped shape decisions regarding CIRM policies and funding. As [vice chair Duane] Roth writes, patient advocates can grasp some of the most complex and thorny policy and scientific issues and "tip the scales" in the direction of sound public policy that seeks prudently to accelerate progress towards cures. ISSCR is kicking off the meeting tonight with a public symposium consisting of patient advocates and scientists discussing progress being made in spinal cord injury (featuring Reed's son Roman Reed), multiple sclerosis and blood disorders. Hopefully those advocate voices will help drive home the importance of continued funding for stem cell research.

A.A.

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